

Synergizing Epidemiologic Research on Rare Cancers

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Methods and Strategies Working Group Group 1

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Question 1: What are the methodological challenges in rare cancer research?

I. Data ascertainment and pooling

- Consistent diagnosis across studies
 - Subtypes, subclassification (e.g. ovarian, NHL)
 - centralized review is difficult and expensive
 - Histologic information difficult to obtain
 - Collect normal tissue (e.g. Liver) & biomarkers
 - Helpful to fill in gaps
 - Need experienced pathologists
 - Requires funding

Question 1: What are the methodological challenges in rare cancer research?

I. Data ascertainment and pooling

- Occupational/Exposure data
 - Consistency and standardization of data collection
 - Agreement on exposure data collection across consortia
 - Fund centralized data management centers
 - Develop a core exposure questionnaire
 - Standardized for cohort and case-control studies

Question 1: What are the methodological challenges in rare cancer research?

II. Statistical issues

- Need to develop new analytical methods
 - Small case numbers & many covariates
 - Limited power
- Need statisticians to understand limitations of rare cancer research (e.g. limited power)
- Forced to pool data
 - Variability of data collection, reliability of data

Question 1: What are the methodological challenges in rare cancer research?

III. Funding for rare cancer research

- Criticism of reviewers regarding power issues and small sample size
 - Develop specific study sections for rare cancers
- Encourage more applications
 - RFA for rare cancer research
- Methodological grants
 - Development of analytical tools
- Funding for data sharing
 - Develop grants to help facilitate standardization of data collection and central data centers

Question 2: What are areas of potential improvements in existing consortia models to foster rare cancer research?

- Mechanisms to support and facilitate data sharing
 - Central data management/coordinating center
 - Standardized exposure collection questionnaire
 - Develop guidelines to assist pre-docs/post-docs/trainees to get involved in rare cancer research and consortia
 - Clarify guidelines for institutional and PI collaboration for analyzing and publishing data from consortia
- Mechanisms to avoid duplication of studies
 - Genome wide scans & SNP analyses
 - Overlap of cases in biomarker & basic science research

Question 3: What are novel strategies in consortia coordination and implementation?

- Supplemental applications for existing R01s in rare cancer research
 - Minority supplements
- Develop new web tools to pool existing data
- Public website to provide information on rare cancer consortia
 - How to join
 - Policy for adding new cohorts to consortia
- Develop open door policy to join consortia
 - Target new investigators

Question 3: What are novel strategies in consortia coordination and implementation?

- Big Science
 - Roadmaps for research after genome wide scans
 - Biomarker research
 - Translate genetic finding to prevention
- Forums and abstract sessions for rare cancers
 - AACR/Frontiers in Cancer Prevention Research
- Develop a symposium for methodological research for rare cancers at national cancer meetings
- Collaborate with Community groups/Foundations
 - Sources of funding
 - Education

Participants

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